

**NEEDS ASSESSMENT SURVEY
OF
RHODE ISLAND WORKING-AGE ADULTS
WITH PHYSICAL DISABILITIES
AND
CHRONIC HEALTH CONDITIONS
ON
FEE-FOR-SERVICE MEDICAID**

Submitted to: Division of Health Care Quality, Financing and Purchasing
Rhode Island Department of Human Services

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for the Health Indicator Project
Medicaid Research and Evaluation Project
February, 2002

Funded by: Center for Health Care Strategies
Princeton, NJ

ACKNOWLEDGEMENTS

There were many people who shared their time and expertise to make this survey a success. Thanks go to Frank Spinelli, MA, Dianne Kayala, MS, and Ellen Mauro, RN, MPH from the Center for Adult Health, the Rhode Island Division of Health Care Quality, Financing and Purchasing. Frank, Dianne and Ellen provided an understanding of the health conditions and concerns of the population to be surveyed and directed our attention to particular issues of interest.

The members of the Evaluation Studies Workgroup as well as program personnel were involved in reviewing the questionnaire, the preliminary data, and this report. The Evaluation Studies Workgroup includes Susan Allen, PhD, Jay Buechner, PhD, Jane Griffin, MPH, Patrick Vivier, MD, PhD and myself. In addition to those from the Center for Adult Health, program personnel include Tricia Leddy, MS, Administrator of the Center for Child and Family Health and Bill White, MPH, and Nora Leibowitz, MPP, of ACS/Birch and Davis.

Susan Allen, Jane Griffin and I took the lead in developing the survey questionnaire and in analyzing the collected data. Richard Arigo directed the survey file production work. Holly Tartaglia produced the report's graphics. Special thanks to Nora Leibowitz for her exacting editorial review.

We were very fortunate to have had dedicated and compassionate interviewers. Thanks go to Magaly Angeloni, Dianne Boghossian, Renee Jarest, Lisa Marshall, Kimly Sao, Holly Tartaglia, Celina Vogel, Karin Wetherill, and Pheamo Witcher.

The most important contribution to this report came from the survey participants themselves. This report would not have been possible without their willingness to share their time, energy and stories of how their health conditions impact their lives.

This work was funded through a Demonstration Grant from the Center for Health Care Strategies (CHCS) made possible through a separate grant to CHCS by the Robert Wood Johnson Foundation. Tricia Leddy, MS is the Project Director on this demonstration grant.

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Table of Contents

	Page
I. EXECUTIVE SUMMARY	V
II. BACKGROUND	1
III. METHODS	4
IV. RESULTS	8
Section 1: Demographic and Social Characteristics of Survey Respondents	9
Section 2: Health Conditions	12
Section 3: Health Status	19
Section 4: Health Services Utilization	21
Section 5: Unmet Needs of Rhode Islanders on Fee-for-Service Medicaid	28
APPENDICES	35
Appendix 1: Detailed Tables	36
Appendix 2: Evaluation Studies Work Group	43
Appendix 3: Survey Questionnaire	45
Appendix 4: Interviewer Training Agenda	58
Appendix 5: Letter to Potential Survey Respondents	59

LIST OF TABLES

TABLE 1: Characteristics of Survey Respondents	10
TABLE 2: Number of Health Conditions per Respondent	12
TABLE 3: Number of Years with Health Conditions	16
TABLE 4: Most Serious Health Problem in the Past Year	16
TABLE 5: Prevalence of Major Types of Health Conditions	18
TABLE 6: Health Status	20
TABLE 7: Usual Place for Medical Care	21
TABLE 8: Have Own Doctor and Number of Yearly Visits	21
TABLE 9: See Other Doctors/Specialists and Number of Yearly Visits	22
TABLE 10: Needed Immediate Medical Care in Past Year	22
TABLE 11: Usual Place of Care by Place for Immediate Care	23
TABLE 12: Number of Emergency Department Visits in Past Year	24
TABLE 13: Number of Hospital Admissions/Nights Spent in Hospital	24
TABLE 14: Health Care Screening Services/Preventive Health Care	25
TABLE 15: Prescription Medications	27
TABLE 16: Problems Obtaining Prescription Medications	27
TABLE 17: Need for Assistance with the Activities of Daily Living and the Extent of Unmet Need	28
TABLE 18: Need for Assistance with the Instrumental Activities of Daily Living and the Extent of Unmet Need	28
TABLE 19: Health Care Service Needs	30
TABLE 20: Top Ten Unmet Needs of Working-Age Adults with Physical Disabilities	31
Appendix Tables:	
TABLE A-1: Detail Data -- Age	36
TABLE A-2: Detail Data -- Sex and Race/Ethnicity	37
TABLE A-3: Detail Data -- Most Serious Health Problem in Past Year	38
TABLE A-4: Nature of Health Problems and Number of Health Problems by Health Status and Health Service Utilization in the Past Year	39
TABLE A-5: Most Serious Health Problem in the Past Year by Health Status and Health Service Utilization in the Past Year	40
TABLE A-6: ADL/IADL Need by Health Status and Health Service Utilization in the Past Year	41
TABLE A-7: Social Support and Isolation by Health Status and Health Service Utilization in the Past Year	42

LIST OF FIGURES

FIGURE 1: Living Arrangements	11
FIGURE 2: Average Number of Days a Week Leave Home	11
FIGURE 3: Number of Health Conditions by Age	13
FIGURE 4: Distribution of Health Conditions	14
FIGURE 5: Distribution of Health Conditions by Gender	15
FIGURE 6: Health Status of Adults with Disabilities on Fee-for-Service Medicaid	19
FIGURE 7: Percent of Respondents Experiencing Pain, Depression and Anxiety Every Day of the Past Month	20
FIGURE 8: Place for Receiving Acute Medical Care by Having Own Doctor	23
FIGURE 9: Health Care Screening Services in the Past Year by Whether You Have Your Own Doctor	26
FIGURE 10: Cancer Screening in Past Year by Whether You Have Your Own Doctor	26
FIGURE 11: Percent of Respondents by Difficulty in Obtaining Medical Care When Needed	32
FIGURE 12: Percent of Respondents Who Receive Help in Obtaining Medical Care	32
FIGURE 13: Difficult/Very Difficult Obtaining Medical Care When Needed (Selected Characteristics of Respondents)	33

I. EXECUTIVE SUMMARY

This statewide survey was one part of a comprehensive needs assessment of working-age Rhode Islanders with physical disabilities on fee-for-service Medicaid. In the survey, information was collected on health status, types and prevalence of health conditions, functional limitations, health services utilization, unmet health service need and social supports.

DEMOGRAPHICS AND SOCIAL CHARACTERISTICS OF SURVEY RESPONDENTS

- Sixty-two percent of the survey respondents were female and 38% were male.
- The average age of the survey respondents was 49.
- Almost 70% of the respondents self-identified their race/ethnicity as White non-Hispanic, 15% as Hispanic, and 9% as Black/African American.
- Forty-two percent of respondents reported living alone and 15% reported leaving home never or less than once per week.
- Nearly 22% reported having no one or only one person to count on to help them in times of need.
- Almost 20% reported not having someone to talk with about their personal feelings, worries or hopes.
- **Having no one to count on when in need of help and having no one to talk with about personal hopes and feelings increases the likelihood of emergency department and hospital use.**

HEALTH CONDITIONS

- Over 83% of the survey respondents reported more than one health condition; nearly 65% of respondents reported more than two health conditions.

- **The more health problems respondents have, the more likely they are to need immediate medical care and to use hospitals and EDs.**
- Nearly 65% of respondents reported having only physical conditions; an additional 29% reported having both physical and mental conditions.
- **Among respondents, those persons with both mental and physical conditions have worse health status, are more likely to require immediate medical care, and have higher rates of hospital and ED use than those persons with only physical conditions.**
- The average number of years respondents have had health conditions is 16 years. Almost 50% of respondents have been experiencing health conditions for 11 or more years.
- Twenty-two percent of respondents reported their most serious health problem of the past year to be musculoskeletal and connective tissue disease; mental disorders ranked second with 14.3%; circulatory diseases third, 11.9%; endocrine/metabolic diseases (including diabetes) fourth, 11.5%; nervous system diseases (including seizure disorders) fifth, 10.8%; and respiratory diseases (including asthma) sixth, 10.6%.
- In total, 38% of all respondents reported heart conditions; 29% suffer depression, anxiety, tension, and other emotional and mental conditions; 23% reported back conditions; 20% arthritis; and 13% asthma.
- **Of all health conditions, those with respiratory diseases had worse health status and more need for medical care than persons with other types of health conditions.**

HEALTH STATUS

- **The overwhelming majority of respondents, 75%, reported fair or poor health status. This is in sharp contrast to the 14.8% of all Rhode Islanders who reported fair to poor health status in the year 2000.**
- **Twenty-five percent of respondents reported that health problems kept them from their usual activities every day of the past month, 33% reported that pain kept them from engaging in their usual activities every day of the past month, 28% reported they felt sad, blue or depressed every day of the past month, and 37% reported they felt worried, tense or anxious every day of the past month.**

HEALTH SERVICES UTILIZATION

- **Working-age adults on Medicaid have multiple health problems resulting in complex needs for health care, medication and supportive chronic care services.**
- Nearly 98% of respondents reported they have a usual place to go for medical care.
- Over 90% of respondents reported having their ‘own doctor’ or health care provider.
- Of the 556 persons who participated in the survey, 346 (62.3%) needed immediate medical care in the past year.
- The vast majority of respondents go to a hospital emergency room when they need immediate medical care.
- Nearly 27% of those with their own doctor go to their doctor’s office when in need of immediate medical care.
- Fifty-five percent of respondents reported they used an emergency department in the past year. Though 17% of respondents had made one such visit, over 38% had made two or more emergency department visits in the past year.
- Over 28% of respondents reported they were hospitalized in the past year. Fourteen percent of respondents had one hospitalization, 11% had two to four hospitalizations and 3% had five or more hospitalization in the past year.
- **Survey respondents who have their own doctors were more likely to receive all types of health care preventive screenings than were those without their own doctors.**
- Over 90% of the survey respondents take prescription medications. On average, respondents take 4.9 prescriptions.

UNMET NEEDS OF RHODE ISLANDERS ON FEE-FOR-SERVICE MEDICAID

- Though the percent of respondents with needs for assistance with the activities of daily living (ADLs) is relatively small, about 25% of those who have these needs are not able to get enough help.
- There is greater need among survey respondents for assistance with the instrumental activities of daily living (IADLs). In particular, nearly 61% of respondents need help going shopping, 49% need help with housework and over 35% need help preparing meals.

- Over 70% of the survey respondents reported having difficulty walking a quarter of a mile and nearly 70% reported having difficulty climbing one flight of stairs.
- **Survey respondents with ADL and IADL needs have significantly worse health status and significantly higher need for medical care than the survey respondents in general. Overall, the presence of ADL and IADL limitations are better predictors of hospitalizations and ED use, fair to poor health status and need for immediate medical care than are the number of health problems, the nature of health problems or social isolation characteristics.**
- Nearly 76% of respondents reported that it is not difficult to obtain medical care when it is needed.
- For the survey respondents, there was low unmet need (less than or equal to 10%) for doctor's appointments, prescription refills, new prescription medications, over-the-counter drugs, transportation to doctors, disposable medical supplies, specialty medical care, and drug or alcohol counseling.
- There was high unmet need (greater than or equal to 20%) for physical/occupational therapy, mental health counseling, eyeglasses, nutritional counseling, dental care, home health aide and homemaker services, peer support and speech therapy.
- **Survey results show that respondents are more successful in meeting their acute care and medical needs than they are in meeting their needs for chronic care support. This finding suggests that more needs to be done to meet the support needs of this population of chronically ill persons with multiple health conditions.**

II. BACKGROUND

Understanding the health care needs of adults with physical disabilities is imperative. In the February 23, 2001 Morbidity and Mortality Weekly Report (MMWR)¹, it was stated that in the United States from 1991-1992 to 1994-1995, the number of persons reporting disabling conditions increased 10% from 49 million to 54 million persons. **In a recent survey of state Medicaid programs conducted by the Kaiser Commission on Medicaid and the Uninsured², it is noted that States “expect increases in enrollment in the aged and disabled categories due to the aging of the population, a new definition of disability and coverage for the working disabled (p. 28).”** The aging of the population, with the concomitant increase in persons living with disabling conditions, has significant financial implications for all States’ Medicaid budgets in that the medical service and prescription drug expenditures for this population are high. As the MMWR states:

Surveillance of disability prevalence and associated health conditions is useful in setting policy, anticipating the service needs of health systems, assisting state programs, directing health promotion and disease prevention efforts, and monitoring national health objectives (p. 120).

In order to find out the health care needs of working-age Rhode Islanders with physical disabilities living in the community, the Center for Health Care Strategies provided funding to the Division of Health Care Quality, Financing and Purchasing for a comprehensive needs assessment. The needs assessment consisted of three research approaches. First, focus groups were held with members of this Medicaid population³. The focus groups were conducted in the late fall of 2000 and addressed access to Medicaid, health service utilization, quality and adequacy of care, unmet need and

suggestions for program change. Two of the major findings in the focus groups were that there was general dissatisfaction with and confusion about prescription medications and that not being able to obtain information about Medicaid services and benefits prevents recipients from playing a role in managing their health problems and serves to increase their feelings of powerlessness. On the basis of these findings, programmatic changes were instituted. To alleviate confusion and dissatisfaction with prescription medications, changes were made to the pharmacy program. The requirement that all prescriptions must be written was eliminated and the limitations on obtaining refills without an original prescription were altered. Also, to assist members in accessing and understanding Medicaid Services and Benefits, new Medicaid Program ID Cards were designed and issued. In particular, member services phone numbers were added to the ID card.

The second needs assessment effort was a 1998-1999 comparison report, based upon Medicaid claims data, of hospital and emergency department (ED) utilization⁴ for working-age Rhode Islanders on fee-for-service Medicaid. This report presented rates of hospitalization and ED use by age, sex and race. The report detailed the leading causes of hospitalizations and ED visits. Finally, the occurrence and frequency of hospitalizations and ED visits per Medicaid recipient were documented. This study found that about 35% of the non-elderly fee-for-service Medicaid enrollees had an emergency department visit in each of the years 1998 and 1999. From 1998 to 1999, there was a 5.5% increase in the percentage of enrollees who had more than one ED visit and a 10% increase in the percentage of persons who had both a hospitalization and an emergency department visit. Results of this study were utilized in the development of a care coordination program, Connect CARRE. The goal of the Connect CARRE program

is to provide comprehensive medical care and support services to Medicaid recipients who have frequent hospitalizations and ED visits in order to lower their rates of hospitalizations and ED visits.

The third needs assessment activity was a statewide survey. The purpose of the survey was to provide baseline quantitative information on health status, types and prevalence of health problems and conditions, the quality of health care, access and barriers to health care, and unmet need for Medicaid enrollees, ages 21-64, with physical disabilities and chronic health conditions living in the community. This report summarizes the findings of the statewide needs assessment survey.

¹ *Prevalence of Disabilities and Associated Health Conditions Among Adults -- United States*, 1999, MMWR, Vol. 50, No. 7.

² *Medicaid Budget Under Stress: Survey Findings for State Fiscal Year 2000, 2001 and 2002*. The Kaiser Commission on Medicaid and the Uninsured, www.kff.org/content/2001/4020/4020.pdf.

³ *Health Care Needs of Adults with Physical Disabilities Living in the community: Results of Four Focus Groups with Rhode Islanders on Fee-For-Service Medicaid*, The Center for Adult Health, Division of Health Care Quality, Financing and Purchasing, Rhode Island Department of Human Services, March, 2001.

⁴ *Hospital and Emergency Department Utilization for Working-Age Rhode Islanders on Fee-For-Service Medicaid: A 1998/1999 Comparison of Health Services Indicators*, The Center for Adult Health, Division of Health Care Quality, Financing and Purchasing, Rhode Island Department of Human Services, June 2001.

III. METHODS

Survey Questionnaire

The Evaluation Studies Work Group determined topics to be covered in the survey (see Appendix 1 for a listing of the Evaluation Studies Work Group members and their affiliations). The topics to be investigated included:

- Health Status
- Types and Prevalence of Health Problems
- Functional Abilities and Limitations
- Health Services Utilization
- Unmet Health Service Need
- Social Supports

A draft set of questions was developed to address these issues and reviewed by the Evaluation Studies Work Group. (The final questionnaire is provided in Appendix 2.)

Survey Sample

Using the computerized Medicaid Management Information System (MMIS), records were selected for fee-for-service Medicaid enrollees who were ages 21-64, enrolled during the 10/1/99-9/30/2000 period, and not living in institutional settings. We were interested in identifying recipients with physical disabilities and so persons identified on the MMIS with severe and persistent mental illness, mental retardation and developmental disabilities were eliminated. In addition, recipients who had a recent hospitalization and/or an emergency department visit with a principle diagnosis of

schizophrenia were also eliminated. We did not, however, eliminate persons who had hospitalizations or ED visits with principal diagnoses for other types of mental disorders, including psychoses, depression, anxiety and substance abuse problems. In both the focus group and the survey, a sizeable proportion of persons with physical disabilities and chronic health conditions were found to suffer emotional and mental disorders, in particular depression, anxiety and post-traumatic stress.

This left a population of 15,106 persons from which we randomly selected a sample of 1,800. Through further investigation, we eliminated duplicate listings, persons who had moved out of state, had been institutionalized, died and those for whom no attempt to contact was made during the survey implementation. The resulting sample contained a total of 1,406 persons. Of the 636 persons we were able to contact, 556 (87.4%) participated in the survey.

Below is a comparison of the sex, age and race/ethnic composition of the survey population with those of the survey respondents. The race/ethnic data were obtained from the MMIS system and are not those reported by respondents during the taking of the survey (See Table 1 for the survey participants' self-reported races and ethnicities). There was a higher proportion of women represented in the survey than in the population. The persons who participated in the survey were also slightly older than the general population. The race/ethnic composition of the survey participants, however, was very similar to that of the general population.

	Population (n=15,106)	Survey Participants (n=556)
SEX		
Female	57.4	62.2
Male	42.6	37.8
AGE		
21-34	17.8	12.1
35-49	39.5	34.7
50-64	42.7	53.2
RACE/ETHNICITY		
White	64.6	66.0
Hispanic	12.4	12.2
Black	10.8	9.4
Asian	2.3	1.8
Other	9.9	10.6

Data Collection and Management

This telephone survey was conducted by a survey coordinator and nine interviewers. All interviewers attended a two-hour training session that entailed interviewing skills, survey coding and practical role plays (see Appendix 3 for the Interviewer Training Agenda). One of the interviewers was assigned to conduct interviews with Spanish-speaking recipients; another interviewer was assigned interviews with Cambodian recipients. A letter from the Administrator of the Center for Adult Health, Rhode Island Department of Human Services was mailed to all persons in the survey sample notifying them that an interviewer might be calling (See Appendix 4). Phone interviews were conducted from March 7 to April 11, 2001.

The survey coordinator and the interviewers met weekly to review surveys and make data management decisions. Each interviewer maintained a follow-up log on surveys assigned to her. The survey coordinator maintained a follow-up log to keep track of each survey and a management decision notebook to document coding decisions. Quality assurance activities included a 5% call-back of each interviewer's completed surveys and an extensive quality check on the data entry processes.

Confidentiality was guaranteed to all survey respondents. Time was spent in the weekly survey meetings discussing issues of patience, courtesy and consideration in the interviewers' interactions with the survey respondents. Interviewers were directed to offer assistance to any survey participant who requested help or expressed any level of distress. Nearly two dozen survey participants requested and were provided assistance from Medicaid Program staff.

IV. RESULTS

Section 1 of this report presents the demographic and social characteristics of the survey respondents. Section 2 details their self-reported health problems and Section 3 profiles their self-reported health status. Section 4 presents self-reported health services utilization data and Section 5 profiles the respondents' activities of daily living (ADL) limitations and their instrumental activities of daily living (IADL) limitations, their needs for health and social services and the extent to which they are able to obtain needed services.

Section 1: Demographic and Social Characteristics of Survey Respondents

Of the survey respondents, 62.2% were female and 37.8% were male. Sixty-two percent of the survey respondents were age 45 and over; the average age of the survey respondents was 49. Almost 70% of respondents self-identified their race/ethnicity as White non-Hispanic. Hispanics were the second largest race/ethnic group, 15% of the respondents, and Black/African Americans were the third largest group, 8.9% of the respondents. (See Tables A-1 and A-2 for detailed cross-tabulations of a selected set of survey topics by sex, age, and race/ethnic detail.) Forty-six percent of the survey respondents had less than a high school education and 8.5% were college graduates.

Social factors as well as medical factors are predictive of health services utilization and health outcomes so in the survey we also collected information on respondents' social characteristics and supports. Forty-two percent of respondents reported living alone and about 15% reported leaving home never or less than once per week. **Nearly 22% reported having no one or only one person to count on to help them in times of need and almost 20% reported not having someone to talk with about their personal feelings, worries or hopes.** Having no one to count on when in need of help and having no one to talk with about personal hopes and feelings increases the likelihood of needing immediate medical care and of emergency department and hospital use. (See Table A-7 for more detail.)

TABLE 1: Characteristics of Survey Respondents

	Number	Percent
Total Survey Respondents	556	
SEX		
Male	210	37.8
Female	346	62.2
AGE		
21-24	10	1.8
25-34	57	10.3
35-44	121	21.8
45-54	146	26.3
55-64	222	39.9
	mean = 49.2	median = 52.0
RACE/ETHNICITY (self-reported)		
White	385	69.7
Black/African American	49	8.9
Asian/Pacific Islander	12	2.2
Spanish/Hispanic	83	15.0
American Indian	9	1.6
Other	14	2.5
HIGHEST GRADE OF SCHOOL COMPLETED		
Less than high school	254	45.8
High school graduate	161	29.0
Some college	93	16.8
College graduate	47	8.5
NUMBER OR PEOPLE YOU FEEL YOU CAN COUNT ON TO HELP WHEN IN NEED OF HELP:		
None	30	5.4
One	91	16.5
Two	93	16.8
Three	91	16.5
Four	71	12.9
Five or more	176	31.2
	mean = 4.9	median = 4.0
		missing = 4
SOMEONE TO TALK TO ABOUT PERSONAL FEELINGS, WORRIES OR HOPES:		
Yes	452	81.4
No	103	18.6
	missing = 1	

Figure 1: Living Arrangements

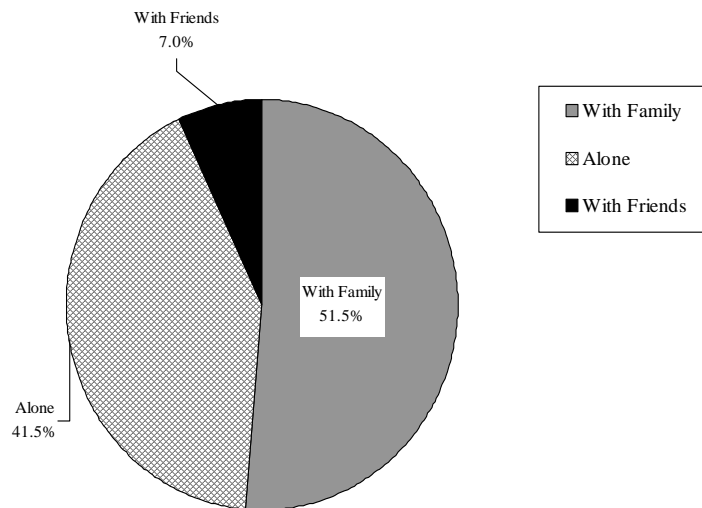
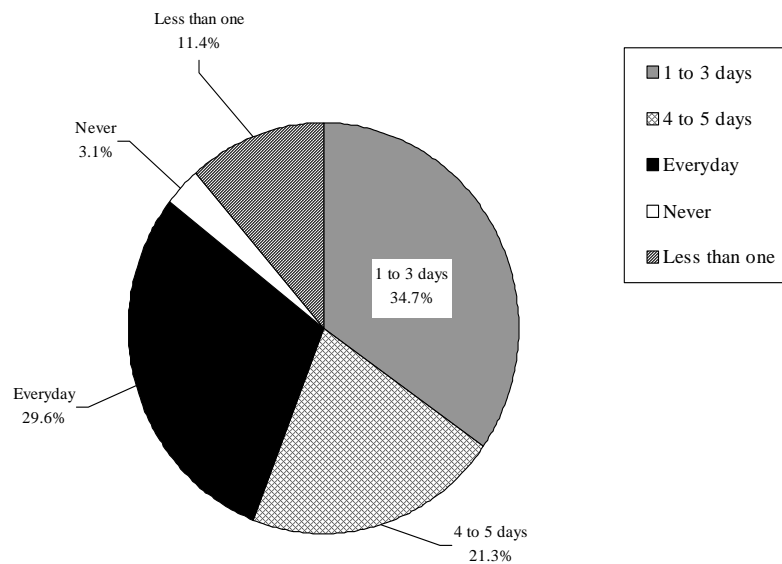


Figure 2: Average Number of Days a Week Leave Home



Section 2: Health Conditions

A major goal of the adults with disabilities needs assessment is to understand the health services utilization patterns of this population, the types and extent of the medical care needed, and the types and extent of unmet need for medical and ancillary health care. These data assist the Rhode Island Department of Human Services to provide and plan for the medical services needed by working-age adults with physical disabilities on fee-for-service Medicaid.

In attempting to reach this goal, two questions were asked to capture information on the nature and types of health problems experienced by this population. First, respondents were asked, ‘What health problems do you have that require medical care or medication?’ (Question 16). And, ‘In the PAST YEAR, what has been your most serious health problem, the health problem that has required the most medical care or medication?’ (Question 18).

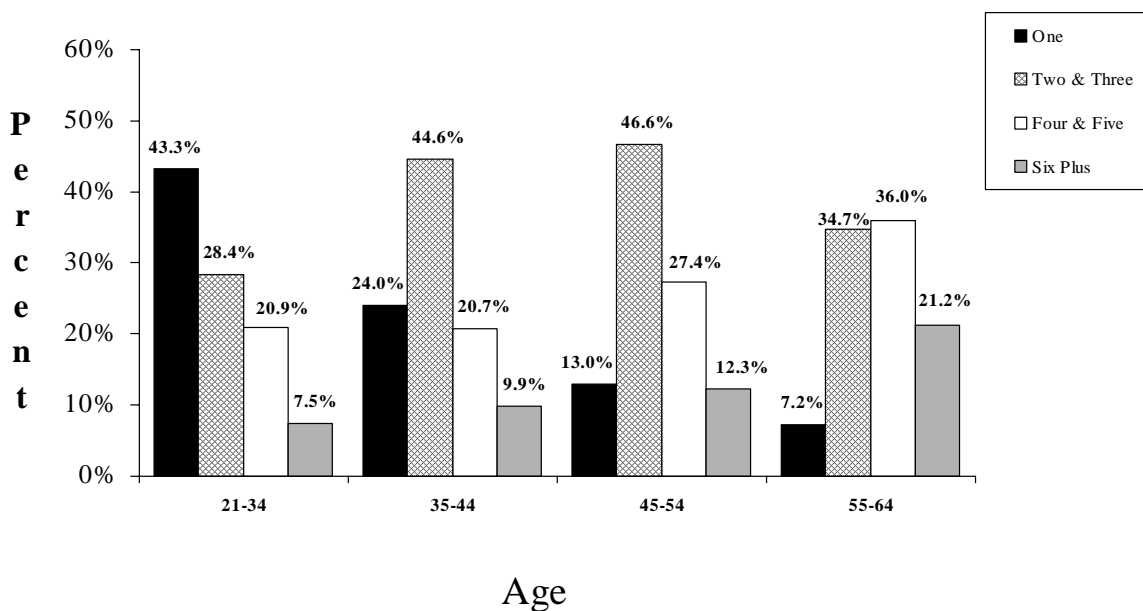
From the responses to these two questions, the number of health conditions per respondent were counted. **Over 83% of the survey respondents reported more than one health condition. The median number of health conditions reported among survey respondents was 3.**

Table 2: Number of Health Conditions per Respondent

Number of Health Conditions	Number	Percent
One	93	16.7
Two	99	17.8
Three	119	21.4
Four	82	14.7
Five	77	13.8
Six or more	82	14.7
mean = 3.5	median = 3	missing = 4

Figure 3 presents the number of health conditions per respondent by age of respondent. As Figure 3 indicates, the number of health problems per respondent increase with age.

Figure 3: Number of Health Conditions by Age



As is to be expected, the more health problems respondents have, the more likely they are to need immediate medical care and to use hospitals and EDs. (See Table A-4 for additional detail.)

Based upon questions 16 and 18, the nature of health problems were tabulated. Figure 4 indicates that 64.8% of the survey respondents reported having only physical health conditions. However, an additional 28.5% reported having both physical and mental conditions. The most commonly reported mental conditions were anxiety, tension, depression or post-traumatic stress. **Among respondents, those persons with both mental and physical conditions have worse health status, are more likely to require immediate medical care, and have higher rates of hospital and ED use than those persons with only physical conditions.** (See Table A-4 for additional details.)

Figure 4: Distribution of Health Conditions

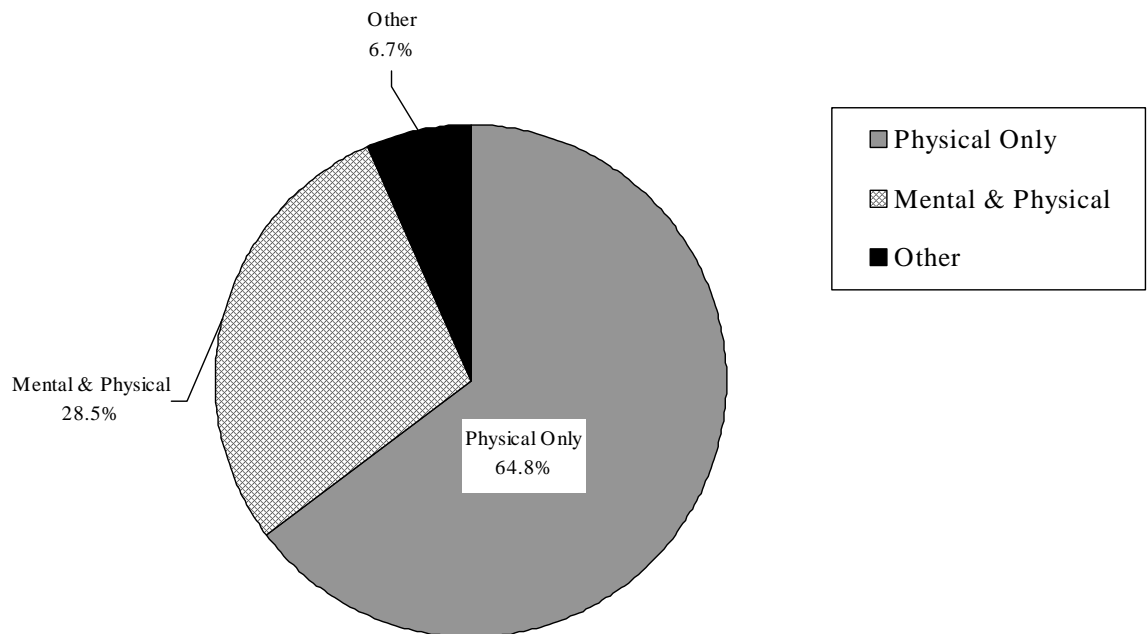
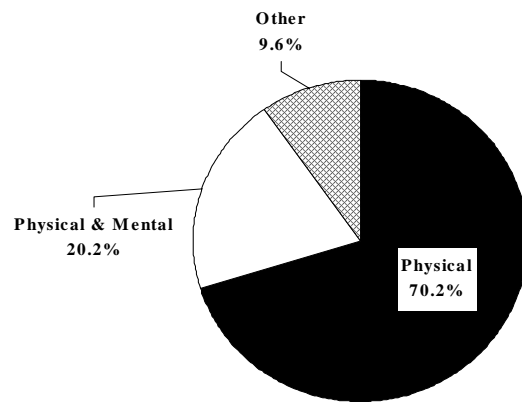
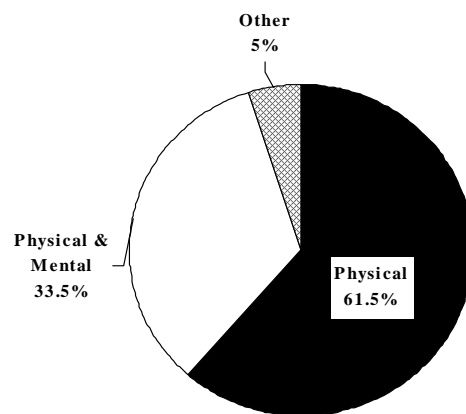


Figure 5 indicates that women were more likely to report having both physical and mental conditions than were men.

Figure 5: Distribution of Health Conditions by Gender



Male



Female

Respondents were asked how many years they have had health problems that require medical care or medication. Table 3 presents a distribution of respondents by the number of years they have had health conditions. **The average number of years respondents have had health conditions is 16 years. Almost 50% of the respondents have been experiencing health conditions for 11 or more years.**

Table 3: Number of Years with Health Conditions

Number of Years	Number	Percent
Four or less	132	23.7
Six to Ten	139	25.0
Eleven to Twenty	121	21.8
Twenty-one or more	156	28.1
mean = 16.1	median = 11.0	missing = 8

The responses obtained to question 18, most serious health problem in the past year, were assigned International Classification of Disease (ICD-9) Codes. Table 4 presents a summarized listing of these health problems in order of most to least frequent. (See Table A-3 for a more detailed ICD-9 listing of respondents' health problems.)

TABLE 4: Most Serious Health Problem In The Past Year

Type of Health Problem	Number	Percent
Musculoskeletal and Connective Tissue Disease (includes arthritis, rheumatism, osteoporosis)	119	22.1
Mental Disorders	77	14.3
Circulatory Diseases (includes hypertension and heart problems)..	64	11.9
Endocrine/Metabolic Diseases (includes diabetes)	62	11.5
Nervous System Diseases (includes epilepsy or other seizure disorders)	58	10.8
Respiratory Diseases (includes asthma)	57	10.6
Digestive System Diseases (includes kidney or liver problem/renal failure)	36	6.7
Cancer/Neoplasms	24	4.5
Other	41	7.6
missing = 18		

Twenty-two percent of respondents reported their most serious health problem of the past year to be musculoskeletal and connective tissue diseases. Mental disorders ranked second with 14.3%; circulatory diseases third, 11.9%; endocrine/metabolic diseases (including diabetes) fourth, 11.5%; nervous system diseases (including seizure disorders) fifth, 10.8%; and respiratory diseases (including asthma) sixth, 10.6%. The results of the Rhode Island needs assessment survey are similar to national data with respect to the most common types of health problems and disabilities.

Prevalence rates for the most common types of health conditions were calculated. The data presented in Table 5 are counts of health problems and not respondents. In other words, a respondent with more than one major type of health condition will be counted in more than one of the listed health problem categories. In this table, the listing of health problems in lower-case are the words used by respondents.

As Table 5 indicates, the most prevalent health condition was heart disease.

Thirty-eight percent of the survey respondents suffered heart conditions. Heart conditions included hypertension, high blood pressure, heart attack or heart by-pass surgery. Twenty-nine percent of respondents suffer depression, anxiety, tension, and other emotional and mental conditions. Twenty-three percent of respondents suffer from back conditions. Twenty-three percent of respondents suffer from arthritis, 20% from diabetes, and 13% from asthma.

Of all health conditions, those with respiratory diseases had worse health status and more need for medical care than persons with other types of health conditions. Other health conditions with severe negative consequences include musculoskeletal disease, circulatory disease and endocrine/metabolic disease. (See Table A-5 for further detail.)

Table 5: Prevalence of Major Types of Health Conditions

PREVALENCE OF RESPONDENTS' HEALTH CONDITIONS	#	%
HEART CONDITIONS: including heart problems or conditions, hypertension, high blood pressure, heart attack, by-pass	212	38.2
DEPRESSION: including depression, anxiety, tension, post-traumatic distress syndrome, mental problems, emotional problems, nerves, very nervous, stress disorder, panic attacks	162	29.2
BACK CONDITIONS: including back problems or pain, spinal problems or pain, spinal damage, disc problems or pain, ruptured or herniated discs	129	23.2
ARTHRITIS: including arthritis, osteoporosis and rheumatism	128	23.1
DIABETES: including diabetes or sugar	112	20.2
ASTHMA	72	13.0
OTHER RESPIRATORY DISEASES: including COPD, emphysema, bronchitis, lung problems and breathing problems	64	11.5
OTHER MENTAL DISORDERS: including bi-polar, paranoia, schizophrenic, developmentally disabled, slow thinking, mental illness	38	6.8

Section 3: Health Status

In that 83% of all respondents have more than one health problem and respondents have been experiencing health problems for an average of 11 years, it is not surprising to find that respondents report fair to poor health status. Figure 6 presents the survey respondents' perceptions of their current health status and their health status today versus their health status one year ago. **The overwhelming majority (75%), reported fair or poor health status.** This is in sharp contrast to the 14.8% of all Rhode Islanders who reported fair to poor health status in the year 2000 (Rhode Island BRFSS). Thirty-five percent of respondents reported their health as being worse now than it was a year ago.

Figure 6: Health Status of Adults with Disabilities on Fee-for-Service Medicaid

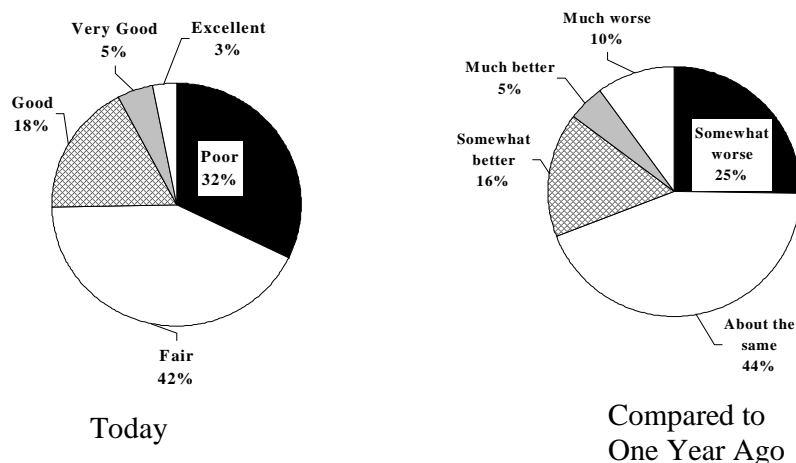


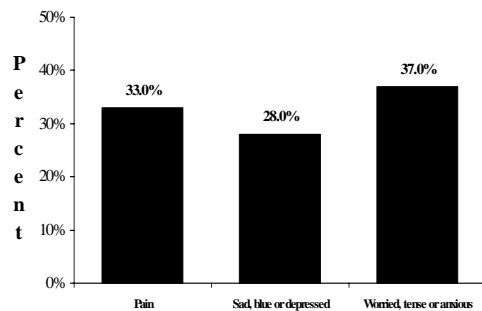
Table 6 presents information on the number of days in the past month when respondents' physical health was not good, their mental health was not good, health problems kept them from engaging in their usual activities, pain kept them from engaging in their usual activities, they felt sad, blue or depressed or they felt worried, tense or anxious. **Substantial proportions of adults on Medicaid report living with continual pain, depression, and anxiety.**

Table 6: Health Status

	Never	1-14 days	15-29 days	Always
Physical health not good	16.7	24.5	22.1	35.4
Mental health was not good	21.6	25.5	23.4	27.5
Health problems kept you from usual activities	24.8	24.1	23.6	24.8
Pain kept you from usual activities	4.8	21.0	19.1	32.9
Felt sad, blue or depressed	18.5	30.6	21.8	27.5
Felt worried, tense or anxious	17.1	27.3	16.4	36.9

Figure 7 shows that 33% of respondents reported that pain kept them from engaging in their usual activities every day of the past month, 28% reported they felt sad, blue or depressed every day of the past month, and 37% reported they felt worried, tense or anxious every day of the past month.

Figure 7: Percent of Respondents Experiencing Pain, Depression and Anxiety Every Day of the Past Month



Section 4: Health Services Utilization

Working-age adults on Medicaid have multiple health problems resulting in complex needs for health care, medication and supportive chronic care services. In this section we profile the health service utilization patterns of the survey respondents.

Nearly 98% of respondents reported they have a usual place for medical care. Fifty-four percent reported that a private doctor's office is their usual place of care, 24% reported their usual place of care is a hospital clinic, and almost 19% reported their usual place of care is a community health center.

Table 7: Usual Place for Medical Care

	Number	Percent
Have a Usual Place for Medical Care	542	97.7% of Respondents
Private Doctor's Office	292	54.0
Hospital Clinic	130	24.0
Community Health Center	101	18.7
Hospital Emergency Room	5	0.9
Walk-in Emergency Room	11	2.0
Other	2	0.4
missing = 1		

Over 90% of respondents reported having their 'own doctor' or health care provider. Of the 502 respondents who reported having their own doctor, the average number of visits they had in the past year with their own doctor or health care provider was 7.6.

Table 8: Have Own Doctor and Number of Yearly Visits

	Number	Percent
Have Own Doctor or Health Care Provider	502	90.5% of Respondents
Number of Visits with own Doctor in Past Year		
None	13	3.6
One to Six	303	60.4
Seven to Twelve	115	22.9
Thirteen or more	66	13.1
mean = 7.6	median = 4	missing = 5

Nearly 74% of respondents reported also seeing other doctors or specialists. The average number of visits with other doctors or specialists in the past year was 9.7.

Table 9: See Other Doctors/Specialists and Number of Yearly Visits

	Number	Percent
See other Doctors/Specialists	409	73.8% of Respondents
Number of Visits with other Doctor in Past Year		
None	9	2.2
One to Six	212	51.8
Seven to Twelve	78	19.1
Thirteen or more	104	25.4
mean = 9.7	median = 3.5	missing = 6

Of the 556 persons who participated in the survey, 346 (62.3%) needed immediate medical care in the past year. Nearly 47% received this immediate medical care in a hospital emergency room, 25% received immediate care at a private doctor's office, and 11% received immediate medical care in a hospital clinic.

Table 10: Needed Immediate Medical Care in Past Year

	Number	Percent
Needed Immediate Medical Care in Past Year	346	62.3% of Respondents
Place where you Received Immediate Medical Care:		
Private Doctor's Office	87	25.2
Hospital Clinic	38	11.0
Community Health Center	26	7.5
Hospital Emergency Room	161	46.7
Walk-in Emergency Room	29	8.4
Other	4	1.2
	missing = 1	

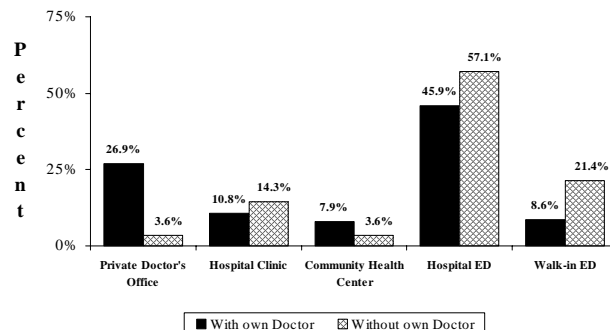
There are strong correlations between respondents' usual places of care and the places they go when they need immediate medical care. Forty-four percent of those whose usual place of care is a private doctor's office also go to their private doctor's office when in need of immediate medical care. Overall, the majority of respondents go to a hospital emergency room when they need immediate medical care.

Table 11: Usual Place of Care by Place for Immediate Care (Percents)

Usual Place of Care:	Place for Immediate Care:				
	Private Doctor's Office	Hospital Clinic	Community Health Center	Hospital ED	Walk-in ED
Private Doctor's Office	44.2	1.7	1.7	40.9	9.9
Hospital Clinic	4.5	34.8	2.3	52.8	4.5
Community Health Center	3.4	6.8	33.9	52.5	3.4
Hospital ED	0.0	0.0	0.0	100.0	0.0
Walk-in ED	0.0	0.0	0.0	0.0	100.0

Figure 8 shows the relationship between whether a respondent has his/her own doctor and the place they go when they are in need of immediate medical care. Nearly 27% of those with their own doctor go to their doctor's office. Those who do not have their own doctor are more likely to go to a hospital emergency room.

Figure 8: Place for Receiving Acute Medical Care by Having Own Doctor



Fifty-five percent of respondents reported they used an emergency department in the past year. Though 16.5% of respondents had made one such visit, over 38% had made two or more emergency department visits in the past year. Overall, the average number of emergency department visits by respondents in the past year was 2.1 visits.

Table 12: Number of Emergency Department Visits in Past Year

	Number	Percent
None	246	44.2
One or more:	304	54.6
One	92	16.5
Two	73	13.1
Three	53	9.5
Four to Seven	64	11.5
Eight or More	22	4.0
mean = 2.1	median = 1.0	missing = 6

Over 28% of respondents reported they were hospitalized in the past year. Over 14% of respondents had one hospitalization, 11% had two to four hospitalizations and 3% had five or more hospitalizations in the past year. For those with a hospitalization, the average number of days spent in the hospital was 3.5 days.

Table 13: Number of Hospital Admissions/Nights Spent in the Hospital

	Number	Percent
None	398	71.6
One or more:	157	28.3
One	80	14.4
Two to Four	62	11.2
Five or more	15	2.7
mean = 0.7	median = 0	missing = 1
For those with a Hospital Admission, Number of Nights Spent in Hospital in Past Year		
One to Three	38	24.2
Four to Seven	45	28.7
Eight to Fourteen	33	21.0
Fifteen to Twenty-one	11	7.0
Twenty-two or more	22	14.0
mean = 3.5	median = 0	missing = 8

Table 14 presents information on the number and percent of survey respondents who received specific types of health care preventive screening services in the past year.

Table 14: Health Care Screening Services/Preventive Health Care

	Number	Percent
Blood Pressure	531	95.7
Blood Sugar/Glucose	411	78.9
Cholesterol	420	79.5
Flu/Pneumonia Vaccine	273	49.5
Physical Check-up	456	82.9
Eye Exam	328	59.3
Colorectal Screening	128	23.4
Breast Exam (female only)	202	59.1
Cervical Pap Smear (female only)	189	55.4
Prostate Screening (male only)	66	32.0

Participants in both the focus groups and the survey (in the final open-ended question) expressed the importance of having their own doctor. **Figures 9 and 10 validate the importance of having one's own doctor in that those survey respondents who have their own doctors were more likely to receive all types of health care preventive screenings than were those without their own doctors.**

Figure 9: Health Care Screening Services in Past Year by Whether You Have Your Own Doctor

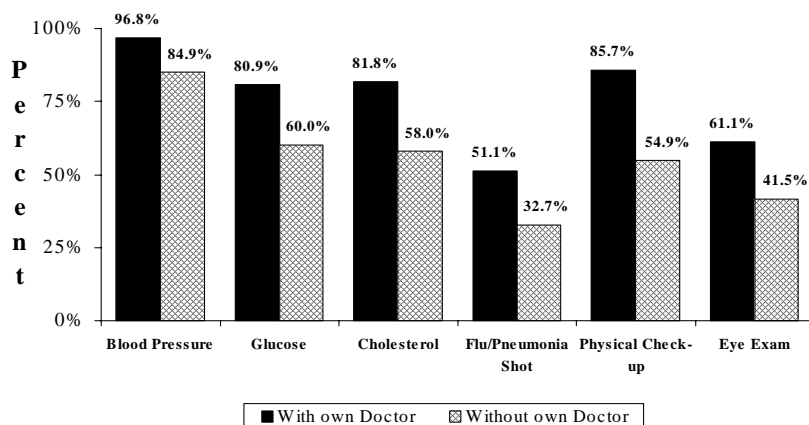
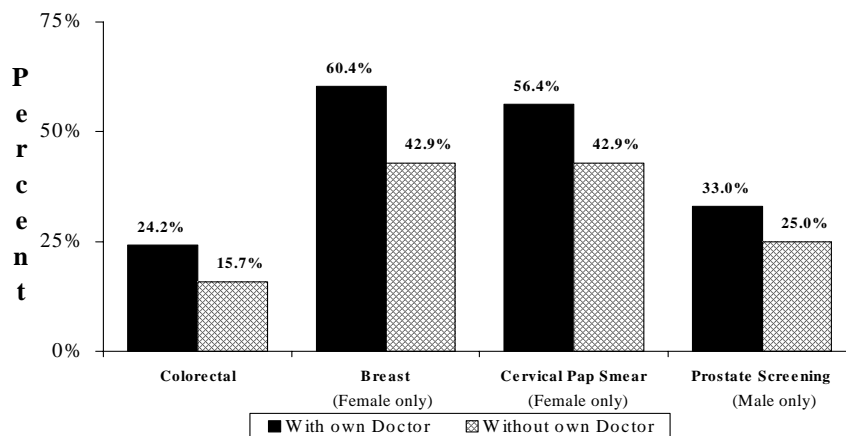


Figure 10: Cancer Screenings in Past Year by Whether You Have Your Own Doctor



Over 90% of the survey respondents take prescription medications. The respondents on average take 4.9 prescription medications.

Table 15: Prescription Medications

Take Prescription Medications	508	91.4% of all Respondents
For those who take Prescription Medications, the number of Prescriptions Medications taken regularly by Respondent		
One to Two	138	27.2
Three to Four	113	22.2
Five to Six	103	20.3
Seven or More	149	29.3
mean = 4.9	median = 4.0	missing = 5

Of those who take prescription medications, 19% had a problem obtaining needed medications in the past year. Among these people, the major problem in obtaining medications was the expense.

Table 16: Problems Obtaining Prescription Medications

	Number	Percent
For those who take Prescription Medications, the number who had a problem obtaining Prescription Medication in Past Year	95	18.9
For those who had a problem, type of problem:		
Couldn't Afford/Medicaid wouldn't pay	58	61.1
Couldn't get to Pharmacy	32	33.7
Needed to talk with Doctor	45	47.4
Needed to Visit Doctor	37	38.9
Couldn't get the Brand they wanted	27	28.4

Section 5: Unmet Needs of Rhode Islanders on Fee-for-Service Medicaid

Tables 17 and 18 present data on functional limitations. Though the percent of respondents with needs for assistance with the activities of daily living (ADLs) is relatively small, about 25% of those who have these needs are not able to get enough help.

TABLE 17: Need For Assistance With the Activities of Daily Living and the Extent of Unmet Need

Activities of Daily Living (ADLs)	Percent who need help	Of Those Who Need Help Percent who do not get enough help
Because of a health problem or disability, do you need help with.....		
Bathing or showering	16.7	22.8
Dressing	16.9	25.5
Eating	5.9	24.2
Getting in and out of bed or chairs	21.8	23.1
Using the toilet	9.7	32.1

There is greater need among survey respondents for assistance with the instrumental activities of daily living (IADLs). **In particular, nearly 61% of respondents need help going shopping, 49% need help with housework and over 35% need help preparing meals. Overall, persons are more able to obtain help with the IADLs than with ADLs.**

TABLE 18: Need For Assistance With the Instrumental Activities of Daily Living and the Extent of Unmet Need

Instrumental Activities of Daily Living (IADLS)	Percent who need help	Of Those Who Need Help Percent who do not get enough help
Because of a health problem or disability, do you need help with.....		
Getting around inside the house	15.6	19.8
Preparing your own meals	35.3	15.8
Going shopping for food/personal items	60.9	11.2
Managing your medication	23.2	9.3
Doing housework	48.9	21.7

In addition to the above ADL and IADL limitations, over 70% of the survey respondents reported having difficulty walking a quarter of a mile and nearly 70% reported having difficulty climbing one flight of stairs.

Survey respondents with ADL and IADL needs have significantly worse health status and significantly higher need for medical care than the survey respondents in general. Overall, the presence of ADL and IADL limitations are better predictors of hospitalizations and ED use, fair to poor health status and need for immediate medical care than are the number of health problems, the nature of health problems or social isolation characteristics. (See Table A-6 for additional detail.)

Table 19 presents a list of medical and ancillary health support services. In the survey, respondents were requested to indicate whether they needed these services in the past year. If a particular service was needed, respondents were requested to indicate if they were able to obtain that service and if it satisfied their need.

Table 19: Health Care Service Needs

In the PAST YEAR did you need...	Percent of Respondents who Needed the Service	Of Those Who Needed the Service in the Past Year:		
		% Not Able to Obtain	% Obtained but didn't Satisfy Need or there was a Problem	% Satisfied
Refills for Prescription Medication	90.5	1.4	12.0	86.7
A Doctor's Appointment	89.4	1.0	11.3	87.7
Over the Counter Drugs	68.7	3.9	35.5	60.5
Dental Care	64.9	31.1	20.3	48.6
New Prescription Medication	63.8	3.7	12.5	83.9
Eyeglasses	62.5	25.1	21.7	53.2
Transportation (to a doctor's office or pharmacy)	52.3	6.9	33.1	60.0
Specialty Medical Care	52.3	8.7	14.9	76.5
Information on your Specific Health Problem	42.0	18.1	20.7	61.2
Mental Health Counseling	36.8	20.6	18.6	60.8
Physical/Occupational Therapy	35.6	21.3	23.9	54.8
Durable Medical Equipment	30.7	10.6	16.5	72.9
Peer Support	30.0	46.1	5.5	48.5
Nutrition Counseling	25.9	28.5	13.2	58.3
Disposable Medical Supplies	24.1	7.5	17.9	74.6
Home Health Aid / Homemaker / Personal Care Services	20.2	32.1	19.6	48.2
Drug or Alcohol Counseling	5.8	6.3	9.4	84.4
Speech Therapy	3.4	47.4	10.5	42.1

There are a number of ways to examine the data in Table 19. One is to contrast those service needs with low (less than or equal to 10%) and high (greater than or equal to 20%) unmet need. There was low unmet need for doctor's appointments, prescription refills, new prescription medications, over-the-counter drugs, transportation to doctors, disposable medical supplies, specialty medical care, and drug or alcohol counseling.

There was high unmet need for physical/occupational therapy, mental health counseling, eyeglasses, nutritional counseling, dental care, home health aide and homemaker services, peer support and speech therapy. Overall, these results suggest that the survey respondents are more successful in meeting their acute care and medical needs than they are in meeting their needs for chronic care support.

More needs to be done to meet the support needs of this population with chronic and multiple health conditions.

A second way to examine these data on unmet service needs is to estimate the number of working-age adults with disabilities on Medicaid who live with unmet need. Table 20 presents an estimate of the number of working-age Rhode Islanders on Medicaid who live with unmet need by type of service needed. Table 20 presents a top-ten ranking of unmet needs in terms of the number of people estimated to be in need.

Table 20: Top Ten Unmet Needs of Working-Age Adults with Physical Disabilities (n=15,106)

Type of Service	Percent of Respondents with Unmet Need	Estimated Number of Adults with Unmet Need
Dental Care	20.2	3,049
Eyeglasses	15.7	2,370
Peer Support	13.8	2,089
Information on specific health problem	7.6	1,148
Physical/Occupational Therapy	7.6	1,145
Mental Health Counseling	7.6	1,145
Nutrition Counseling	7.4	1,115
Home Health Aid/Homemaker/Personal Care	6.5	980
Specialty Medical care	4.6	687
Transportation (to Dr.'s office or Pharmacy)	3.6	545

* Total Population = 15,106 non-elderly adults with physical disabilities on fee-for-service Medicaid

** Estimated Number of Adults with Unmet Need = Number who need service X percent who were not able to obtain service

Figure 11 indicates that the survey respondents are successful in obtaining medical care when needed. **Nearly 76% of the respondents reported that it is not difficult to obtain medical care when it is needed.** Figure 12 shows that 59% of all respondents reported they receive help in obtaining medical care and that nearly 71% who receive help, receive help from their family members or friends.

Figure 11: Percent of Respondents by Difficulty in Obtaining Medical Care When Needed

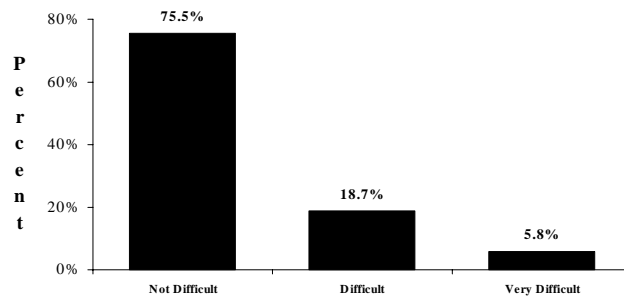
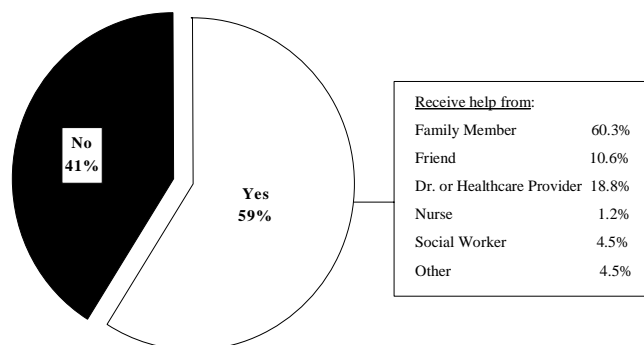
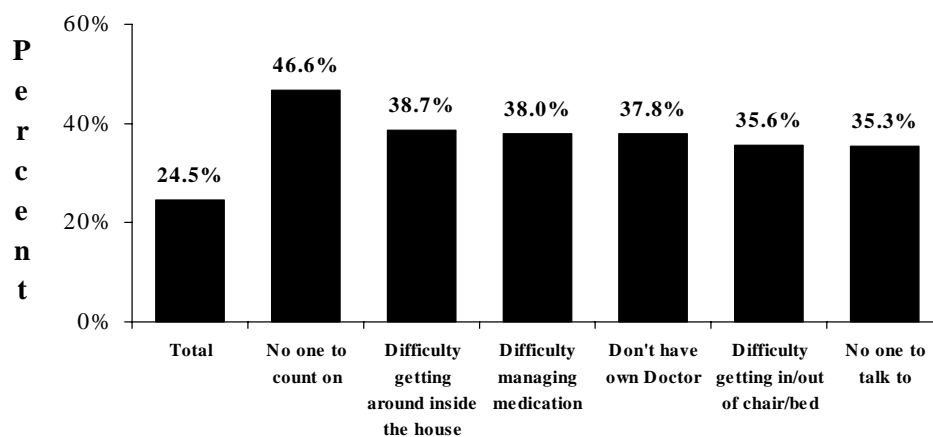


Figure 12: Percent of Respondents Who Receive Help in Obtaining Medical Care



Almost 25 % of respondents reported that it is difficult or very difficult to obtain medical care when they need it. The percent of respondents who had difficulty obtaining medical care, however, varied by characteristics of respondents. Figure 13 indicates that 46.6% of respondents who do not have anyone to count on when they need help find obtaining medical care difficult or very difficult. Over 35% of those who have difficulty getting around inside the house, managing medication, getting in/out of chairs, who don't have their own doctor or have no one to talk to about personal hopes and worries find obtaining medical care when they need it difficult or very difficult.

Figure 13: Difficult/Very Difficult Obtaining Medical Care When Needed by Selected Characteristics of Respondents



Difficulty in obtaining medical care and receiving help in obtaining medical care vary among race/ethnic groups (See Table A-1). Though 26% of White non-Hispanics and 24% of Hispanics find obtaining medical care to be difficult or very difficult, only 14% of African Americans find obtaining medical care difficult or very difficult. This is surprising given that 51% of African Americans receive no help in obtaining medical care whereas only 27% of Hispanics receive no help in obtaining medical care. The African American population, however, has a higher dependency on the formal system for providing help in obtaining medical care, 20.4%, in contrast to 16.4% for Whites and 12.1% for Hispanics. These data, along with other social characteristics presented in Table A-1, suggest that though the Hispanic population is less socially isolated than the African American population, they are less connected to the medical establishment than are African Americans thus making access to medical care more difficult for Hispanics. Language, recent immigration and other cultural differences may explain the difficulty Hispanics face in accessing the medical system.

APPENDICES

TABLE A-1: DETAIL DATA -- AGE (Percents)

		AGE			
	TOTAL	21 - 34	35 - 44	45 - 54	55 - 64
Total Number	556	67	121	146	222
Type of Health Problem					
Physical Only	64.8	59.1	60.8	63.5	69.6
Physical and Mental	28.5	21.2	29.2	33.1	27.3
Number of Health Problems					
One	16.7	43.3	24.0	13.0	7.2
Two or Three	39.2	28.4	44.6	46.6	34.7
Four or Five	28.6	20.9	20.7	27.4	36.0
Six or More	14.8	7.5	9.9	12.3	21.2
Have Own Doctor, Yes:	90.5	82.1	90.8	89.7	93.2
Getting Medical Care:					
Not Difficult	75.5	70.2	66.1	78.8	80.1
Difficult	18.7	23.9	25.6	16.4	14.9
Very Difficult	5.8	6.0	8.3	4.8	5.0
Get Help for Care:					
No, Self	40.6	41.8	40.5	37.0	42.8
Informal Only	42.1	52.2	40.5	42.5	39.6
Formal Only	17.3	6.0	19.0	20.6	17.6
Living Arrangements:					
Live Alone	41.6	17.9	24.8	47.3	54.1
With Family	51.4	73.1	68.6	48.0	37.8
With Roommate	7.0	9.0	6.6	4.8	8.1
Someone to talk to, yes:	81.4	82.1	77.5	80.1	84.2
Someone to count on:					
No one	5.4	6.0	4.1	7.5	4.5
One person	16.4	9.0	19.8	9.6	21.2
Two or more	77.5	83.6	76.0	82.9	73.0
Emergency Department Visit, Yes:	54.6	55.2	57.9	54.8	52.7
Hospital Admissions, Yes:	28.3	20.9	28.9	25.3	32.0

TABLE A-2: DETAIL DATA -- SEX AND RACE/ETHNICITY (Percents)

	TOTAL	SEX		RACE/ETHNICITY		
		MALE	FEMALE	WHITE	BLACK	HISPANIC
Total Number	556	210	346	384	49	83
Type of Health Problem						
Physical Only	64.8	70.2	61.5	62.7	72.9	74.4
Physical and Mental	28.5	20.2	33.5	29.8	20.8	23.2
Number of Health Problems						
One	16.7	21.0	14.2	16.9	22.5	13.3
Two or Three	39.2	40.0	38.7	40.8	40.8	28.9
Four or Five	28.6	29.1	28.3	26.2	24.5	39.8
Six or More	14.8	9.5	17.2	15.6	12.2	16.9
Have Own Doctor, Yes:	90.5	88.6	91.6	90.7	91.8	91.5
Getting Medical Care:						
Not Difficult	75.5	75.7	75.4	73.7	85.7	77.1
Difficult	18.7	18.6	18.8	18.8	10.2	21.7
Very Difficult	5.8	5.7	5.8	7.6	4.1	1.2
Get Help for Care:						
No, Self	40.6	40.5	40.8	44.2	51.0	26.5
Informal Only	42.1	44.8	40.5	39.5	28.6	61.5
Formal Only	17.3	14.8	18.8	16.4	20.4	12.1
Living Arrangements:						
Live Alone	41.6	34.8	45.7	45.7	44.9	26.5
With Family	51.4	54.3	49.7	46.2	46.9	72.3
With Roommate	7.0	11.0	4.6	8.1	8.2	1.2
Someone to talk to, yes:	81.4	81.9	81.2	79.7	75.5	90.4
Someone to count on:						
No one	5.4	5.7	5.2	5.5	8.2	3.6
One person	16.4	12.4	18.8	14.6	16.3	22.9
Two or more	77.5	81.4	75.1	79.5	75.5	72.3
Emergency Department Visit, Yes:	54.6	55.7	54.1	53.5	65.3	56.6
Hospital Admissions, Yes:	28.3	28.1	28.3	26.2	34.7	34.9

Table A-3: Most Serious Health Problem in Past Year

	ICD-9 Approximate Codes	#	%
Infectious and Parasitic Diseases	001-139	18	3.3
Cancer / Neoplasms	140-239	24	4.5
Endocrine, Nutritional and Metabolic Diseases, And Immunity Disorders	240-279	62	11.5
Diabetes	240	41	7.6
Mental Disorders	290-319	77	14.3
Developmental Disabilities	317	6	1.1
Nervous System and Sense Organs	320-389	58	10.7
Epilepsy or other seizure disorder	345	26	4.8
Circulatory System	390-459	64	11.9
Hypertension	401	27	5.0
Heart Problems	410	28	5.2
Respiratory System	460-519	57	10.6
Asthma	493	20	3.7
Digestive System	520-579	36	6.7
Kidney or liver problem/renal failure	570	15	2.8
Diseases of the Genitourinary System	580-629	1	0.2
Infections of Skin and Subcutaneous Tissue	680-709	3	0.6
Diseases of the Musculoskeletal System and Connective Tissue	710-739	119	22.1
Arthritis, Rheumatism, Osteoporosis	714	35	6.5
Symptoms, Signs and ill-defined Conditions	780-799	7	1.3
Injury and Poisoning	800-999	4	0.7
Pain – unspecified/severe/chronic		5	0.9
Complications due to surgery, medical care or medication		3	0.6

TABLE A-4: NATURE OF HEALTH PROBLEMS AND NUMBER OF HEALTH PROBLEMS BY HEALTH STATUS AND HEALTH SERVICE UTILIZATION IN PAST YEAR (Percents)

	Total		Health Status	Needed Immediate Care	ED Visit	Hospital Admission
	#	%	Fair to Poor			
TOTAL	556	100.0	74.9	62.3	54.6	28.3
Nature of Health Problems						
Physical Only	357	64.8	74.5	60.5	53.5	28.6
Mental and Physical	157	28.5	86.0	73.7	62.4	32.5
Number of Health Problems						
One	93	16.7	45.2	37.6	45.2	22.6
Two or Three	218	39.2	74.8	59.9	52.3	26.2
Four or Five	159	28.5	88.7	69.8	56.0	29.6
Six or More	82	14.7	84.2	82.9	70.7	39.0

TABLE A-5: MOST SERIOUS HEALTH PROBLEM IN THE PAST YEAR BY HEALTH STATUS
AND HEALTH SERVICE UTILIZATION IN PAST YEAR (Percents)

	Total		Health Status	Needed Immediate Care	ED Visit	Hospital Admission
	#	%	Fair to Poor			
TOTAL	538	100.0	74.9	62.3	54.6	28.3
TYPE OF HEALTH PROBLEM						
Musculoskeletal and Connective Tissue Disease	119	22.1	83.2	69.8	57.1	22.7
Mental Disorders	77	14.3	67.5	53.3	52.0	19.5
Circulatory Diseases	64	11.9	82.8	59.4	57.1	37.5
Endocrine/Metabolic Diseases	62	11.5	80.6	62.9	54.8	24.2
Nervous System Diseases	58	10.8	54.5	50.0	41.3	19.0
Respiratory Diseases	57	10.6	87.7	84.2	66.7	45.6
Digestive System Diseases	36	6.7	62.8	60.0	55.6	41.7
Cancer/Neoplasms	24	4.5	70.8	58.3	54.2	37.5
Other	41	7.6	78.0	61.0	56.1	31.7

TABLE A-6: ADL/IADL NEED BY HEALTH STATUS AND HEALTH SERVICE UTILIZATION
IN PAST YEAR (Percents)

	Total		Health Status	Needed Immediate Care	ER Visit	Hospital Admission
	#	%	Fair to Poor			
TOTAL	556	100.0	74.9	62.3	54.6	28.3
ADL NEED						
Bathing or Showering	93	16.7	80.7	71.0	65.6	43.0
Dressing	94	16.9	79.8	77.7	67.0	48.9
Eating	33	5.9	57.6	69.7	60.6	39.4
Getting in/out of bed or chairs	121	21.8	86.8	74.4	67.8	41.3
Using the toilet	54	9.7	75.9	70.4	59.3	46.3
IADL NEED						
Getting around inside the house	87	15.7	85.1	74.7	62.1	44.8
Preparing your own meals	196	35.3	82.1	70.9	61.2	38.8
Go shopping for food/personal items	338	60.9	81.7	68.3	58.0	32.3
Managing your medication	129	23.2	78.3	74.2	63.6	38.0
Doing Housework	272	48.9	84.2	72.7	59.6	35.3

TABLE A-7: SOCIAL SUPPORT AND ISOLATION BY HEALTH STATUS AND HEALTH SERVICE UTILIZATION IN PAST YEAR (Percents)

	Total		Health Status	Needed Immediate Care	ER Visit	Hospital Admission
	#	%	Fair to Poor			
TOTAL	556	100.0	74.9	62.3	54.6	28.3
Help Getting Medical Care:						
Self/No Help	226	40.6	76.1	61.5	56.2	27.0
Formal Only	96	17.3	74.0	56.3	50.0	25.0
Informal Only	234	42.1	73.5	65.7	55.1	30.8
Living Arrangements:						
Alone	231	41.5	78.4	65.8	56.3	31.2
Family	286	51.4	72.4	60.4	52.8	27.3
Roommates	39	7.0	69.2	56.4	59.0	18.0
Person to Count on:						
No one	30	5.4	76.7	80.0	70.0	30.0
One	91	16.5	82.4	63.3	56.0	34.1
Two or More	431	77.4	72.6	61.3	53.4	27.2
Someone to talk to:						
Yes	452	81.4	75.2	61.2	54.0	26.8
No	103	18.6	72.8	68.0	58.3	35.0

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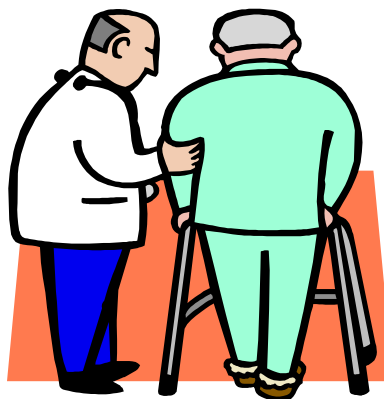
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HEALTH CARE NEEDS OF ADULTS WITH DISABILITIES SURVEY



Conducted by: MCH Evaluation, Inc.
For the Center for Adult Health, Department of Human Services
March 2001

Funded by: Center for Health Care Strategies
Princeton, NJ

**HEALTH CARE NEEDS OF ADULTS WITH DISABILITIES SURVEY
FEE-FOR-SERVICE MEDICAID ENROLLEES AGES 21-64**

Name: _____	Dates of attempt/follow-up: _____
Address: _____ _____ _____	_____ _____ _____
Phone: _____	_____ _____
Survey ID: _____	_____
Other: _____ _____ _____	

INTRODUCTION TO THE PHONE CALL INTERVIEW

Hello, this is _____ calling on behalf of the Department of Human Services. We sent you a letter a few days/weeks ago inviting you to answer survey questions. We are talking to you today so we can improve services to adults with serious and long-term health problems.

Are you (Name from above)_____

Did you receive the letter? (If no, may I read it to you?)

Do you have any questions?

The survey takes about 15-20 minutes.

Do you have time now or can I call back at a better time?

All the information you give in this survey is confidential and no one who participates in this survey will be identified in any way. You only have to answer questions you feel comfortable answering. There will be no change in your services or benefits whether or not you participate in this survey.

FILL OUT THIS SHEET FOR ALL CASES SELECTED FROM LOG

1. Recipient's Date of Birth _____ / _____ / _____

2. Recipient's Age _____

3. City/Town of Residence (1-39) _____

4. Race/Language (1=White 2=Hispanic 3=Black 4=Asian 5=other) _____ / _____
1=English 2=Spanish 3=Portuguese 4=Cambodian 5=other)

5. Sex (1=male 2=female) _____

6. TPL Status (0=no 1=yes) _____

7. Aid Category (AD etc.) _____

8. Date enrolled in Medicaid _____ / _____ / _____

9. Survey ID Number _____

10. MID Number _____

11. Number of Attempts to Contact Client _____

12. Follow-up Status _____

1 = Completed Interview

2 = Able to contact -- Declined Interview

3 = Unable to contact – (no working phone)

4 = Unable to contact – (have phone, no answer)

5 = Deceased

6 = Moved Out of State

7 = Other

8 = Caretaker completed questionnaire

9 = Respondent incapable of completing questionnaire

10 = Questionnaire completed with assistance of Interpreter

13. Date of Actual Interview _____ / _____ / _____

14. In general, would you say your health is: [Read All]

Excellent	1
Very good	2
Good	3
Fair	4
Poor	5

15. Compared to one year ago, how would you rate your health now? [Read All]

Much better now than one year ago	1
Somewhat better now than one year ago	2
About the same as one year ago.....	3
Somewhat worse now than one year ago.....	4
Much worse now than one year ago	5

16. What health problems do you have that require medical care or medication? [List All]

_____ / _____

17. How many years have you had health problems that require medical care or medication? _____

18. In the PAST YEAR, what has been your most serious health problem, the health problem that has required the most medical care or medication?

_____ / _____

19. Concerning your physical health, which includes physical illness and injury, for how many days during the past 30 days was your physical health not good? _____

20. Concerning your mental health, which includes stress, depression, and problems with emotions, for how many days during the past 30 days was your mental health not good? _____

21. During the past 30 days, for about how many days did poor physical or mental health keep you from doing your usual activities, such as self-care, work, or recreation? _____

22. During the past 30 days, for about how many days did pain make it hard for you to do your usual activities such as self-care, work, or recreation? _____
23. During the past 30 days, for about how many days have you felt sad, blue, or depressed? _____
24. During the past 30 days, for about how many days have you felt worried, tense, or anxious? _____

Now we'd like to ask you some questions about how your health problems affect your daily life.

Activity Because of a health problem or disability, do you need help with...	0 = No 1 = Yes	Do you get enough help? 0 = No 1 = Yes
25. Bathing or showering	0 1	0 1
26. Dressing	0 1	0 1
27. Eating	0 1	0 1
28. Getting in and out of bed or chairs	0 1	0 1
29. Using the toilet	0 1	0 1
30. Getting around inside the house	0 1	0 1
31. Preparing your own meals	0 1	0 1
32. Going shopping for food or personal items	0 1	0 1
33. Managing your medication	0 1	0 1
34. Doing housework	0 1	0 1

35. Do you have a hard time climbing one flight of stairs?

No	0
Yes	1

36. Do you have a hard time walking a quarter of a mile -- about three city blocks?

No	0
Yes	1

Now we'd like to ask you some questions about your medical care.

37. Is there a usual place you go for your medical care?

No [go to 39]	0
Yes	1

38. Where do you usually go for medical care?

(Private) Doctor's office	1
Hospital Clinic	2
Community Health Center	3
Hospital Emergency Room	4
Walk-In Emergency Room/Treatment Center	5
Other	6
Specify: _____	

39. Do you have your own doctor or health care provider?

No [go to 41]	0
Yes _____	1
Name of Doctor	

40. In the past year, how many visits or check-ups did you have with your own doctor?

41. Do you see any other doctors or therapists (such as a cardiologist, a urologist, an oncologist, a respiratory therapist, or psychologist)?

No [go to 43]	0
Yes	1

42. In the past year, how many visits did you have with these other doctors or therapists? _____

43. In the past year, have you ever been sick and needed to see a doctor right away?

No [go to 45]	0
Yes	1

44. Where did you go the last time you were sick and needed to see a doctor right away?

(Private) Doctor's office	1
Hospital Clinic	2
Community Health Center	3
Hospital Emergency Room	4
Walk-In Emergency Room	5
Other	6
Specify: _____	

In the past year, have you had:

	No	Yes
45. Your blood pressure checked?	0	1
46. Your blood checked for glucose or sugar?	0	1
47. Your cholesterol level checked?	0	1
48. A flu shot or a pneumonia shot?	0	1
49. Physical check-up/exam?	0	1
50. An eye exam?	0	1

In the past year, have you had any cancer screenings such as:

51. (for both men and women) colorectal cancer screening such as a fecal blood test or a colonoscopy)?	0	1
52. (for women)a breast exam or a mammogram	0	1
53. (for women) a cervical pap smear	0	1
54. (for men) prostate screening	0	1

We're doing really well. Right now we are about halfway done.

55. In the past year, how many times have you gone to a hospital emergency room? _____

56. In the past year, how many times have you been admitted to the hospital? [If none, go to 58] _____

57. In the past year, how many nights did you spend in the hospital? _____

58. Overall, how difficult is it for you to get medical care when you need it? Would you say it is.... [Read Responses]

Not Difficult 0

Difficult..... 1

Very Difficult 2

59. Does anyone help you get the medical care and services you need?

No [go to 61]..... 0

Yes 1

60. Who helps you get the medical care and services you need?

Family member 1

Friend 2

Doctor or health care provider 3

Nurse 4

Social Worker 5

Other person..... 6

We've talked with some people who also receive Medicaid benefits about what they wish the Medicaid program would do for them. Now we'd like to get your opinion on what these people told us. For each statement, we'd like you to tell us if these things are not important to you, important to you, or very important to you.

For you, is it:

		Not Important	Important	Very Important
61.	To receive a list of doctors who will accept Medicaid patients	0	1	2
62.	To receive information on what services and benefits the Medicaid Program provides	0	1	2
63.	To receive information on your specific health problems	0	1	2
64.	To have a phone number to call when you have questions or problems with your medical care	0	1	2
65.	To receive information on what prescription medications the Medicaid Program pays for	0	1	2

I am going to read you a list of medical and support services you may have needed in the PAST YEAR. In the PAST YEAR did you need.....	0 = no, do not/did not need the service 1= yes, need/ed the service [go to next column]	Were you able to obtain? 0 = not able to get 1 = yes, got it but didn't satisfy me or I had a problem 2 = yes, got it & it satisfied me and I did not have a problem
66. Physical Therapy/Occupational Therapy	0 1	0 1 2
67. Speech Therapy	0 1	0 1 2
68. home health aide/homemaker services/personal care services	0 1	0 1 2
69. mental health counseling	0 1	0 1 2

In the PAST YEAR did you need.....	0 = no, do not/did not need the service 1= yes, need/ed the service [go to next columns]	Were you able to obtain? 0 = not able to get 1 = yes, got it but didn't satisfy me or I had a problem 2 = yes, got it & it satisfied me and I did not have a problem
70. nutrition counseling	0 1	0 1 2
71. information on your specific health problem	0 1	0 1 2
72. new prescription medications	0 1	0 1 2
73. refills for prescription medications	0 1	0 1 2
74. over the counter drugs	0 1	0 1 2
75. eyeglasses	0 1	0 1 2
76. durable medical equipment	0 1	0 1 2
77. disposable medical supplies	0 1	0 1 2
78. transportation (to doctor's or pharmacy)	0 1	0 1 2
79. a doctor's appointment	0 1	0 1 2
80. specialty medical care	0 1	0 1 2
81. dental care	0 1	0 1 2
82. drug or alcohol counseling	0 1	0 1 2
83. ...or want to talk with other people with similar health problems	0 1	0 1 2

Now we'd like to ask you some questions about prescription medications.

84. Do you take any prescription medications?

No [go to 93]	0
Yes	1

85. How many prescription medications do you take on a regular basis? _____

86. In the past year, have you ever had any problems getting prescription medication?

No [go to 93]	0
Yes	1

We now want to tell you some of the problems other people have had getting prescription medication and ask you if you have had the problem. [Read Each]

Have you had any of problems getting your prescription medication because...

	No	Yes
87. You didn't have the money	0	1
88. Medicaid wouldn't pay for it	0	1
89. You couldn't get to the pharmacy (needed transportation)	0	1
90. You needed to talk with the Doctor to get the prescription	0	1
91. You needed to visit the Doctor to get the prescription	0	1
92. You couldn't get the brand you wanted	0	1

93. On average, about how many times per week do you leave your house or apartment building? Would you say you... [Read]

Never leave your home or apartment	0
Leave less than once per week	1
Leave one to three times per week	2
Leave four or five times per week, or	3
Leave every day	4

94. How many people do you feel you can count on to help you when you need help? _____

95. Do you have someone you can talk to about your personal feelings, worries, or hopes?
- No..... 0
- Yes 1
96. What is your race/ethnicity?
- White..... 1
- Black/African American 2
- Asian/Pacific Islander 3
- Spanish/Hispanic..... 4
- American Indian..... 5
- Other 6
97. What is the highest grade of school you have completed?
- Less than high school..... 1
- High School Graduate 2
- Some college 3
- College Graduate 4
98. Who do you live with?
- Alone 0
- Family 1
- With friend(s)/roommate(s)..... 2
99. How many years have you been receiving Medicaid benefits (enrolled in the Medicaid Program)? _____
100. Besides Medicaid and SSI, do you have any other health insurance coverage?
- No [go to 101]..... 0
- Yes 1
- Don't Know 9

101. If yes, what is this health insurance?

Medicare	1
Private	2
Other	3

102. Can you suggest any changes to the Medicaid Program that would help you to better take care of your health and your medical needs?

[illegible]

Thank you for taking the time to help us find out how the medical system is working for adults with disabilities in Rhode Island. Your answers, along with hundreds of others, will help improve our programs.